

# HIV/AIDS

HEALTH CARE

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UTILIZATION &

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MEDICAL

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ADHERENCE ISSUES

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among HIV Seropositive  
African American Women in Miami

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U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES  
Public Health Service  
Health Resources and Services Administration

MH95D2319



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U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES  
Public Health Service  
Health Resources and Services Administration  
Bureau of Health Resources Development  
DHHS Publication No. HRSA RD-SP-93-5



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**HEALTH CARE UTILIZATION AND MEDICAL  
ADHERENCE ISSUES AMONG PRENATAL HIV  
SEROPOSITIVE AFRICAN AMERICAN WOMEN IN MIAMI:**

**THE ROLE OF THE FAMILY AND THE EXTENDED KINSHIP  
NETWORK**

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## Abstract

**F**our pregnant, HIV seropositive African American women and their families were interviewed to explore family and extended kinship network influences on health care utilization and medical adherence. The major factors that emerged as relevant to health care in the lives of all four women were: 1) transportation, 2) child care, 3) the pregnancy and concern for the unborn child's health, 4) the presence of a concerned/involved family member, and 5) substance abuse. The study supports the conclusion that families and extended kinship networks are significant influences on the use of health care services by pregnant African American HIV seropositive women.

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This work was supported by the U.S. Department of Health & Human Services, Public Health Service, Health Resources and Services Administration, Bureau of Health Resources Development, Rockville, Maryland, Order #HRSA 91-1016(P). This report is published in *Family Systems Medicine*, Vol. II, No. 4, 1993, pp. 1-14

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## Introduction

Trends in reported cases of AIDS in the United States clearly indicate that HIV infection rates are increasing among women and infants <sup>(1,3,15,16,19)</sup>. These increasing rates are disproportionately high among African Americans <sup>(10,16)</sup>. Effective use of health care services by pregnant women who are HIV positive is of the utmost importance. For example, a review of the attendance records of the target population at the University of Miami/Jackson Memorial Medical Center's Special Immunology Prenatal Clinic revealed a high rate of missed appointments. Clinic attendance was reviewed for a randomly selected week. Of 38 women who were scheduled to attend clinic, only 24 showed, representing a 36 percent failed appointment rate. Clearly there is a need to discover the factors that influence one-third of the clients' failure to keep their clinic appointments, especially since federal funding for prenatal care of HIV seropositive women has been increased through the Pediatric Services Demonstration Projects and the Ryan White CARE Act <sup>(7)</sup>. This exploratory study examines the effects of significant family members and extended kinship networks on use of and adherence to health care services by HIV seropositive pregnant women.

Four pregnant, HIV seropositive African American women were selected for this pilot study from the patient population of the Obstetrics and Gynecology Special Immunology Prenatal Clinic of the University of Miami/Jackson Memorial Hospital. They represent a range of medical adherence in the African American patient population observed by case managers and the clinic staff during almost 3 years of clinic operation. Each woman was contacted individually in the clinic by her case manager and asked if she would participate in a project that involved a "family interview" related to the use of health care services for HIV seropositive African American women. All of the women initially selected and contacted agreed to participate. They then were asked to designate family members or significant others to bring to the interview. The women were informed that they would receive \$75 for participation. Financial

circumstances did not represent a barrier to either the quality or the availability of prenatal or HIV-related medical treatment for the women. Additionally, at Jackson Memorial Hospitals and clinics there is an elaborate network of case managers, social workers, and field workers whose primary responsibility is to maintain clients, such as these women, in the health delivery system. The more serious the medical condition, the more intensely the client is pursued.

Because of the importance of the family's influence on individual health-seeking behaviors,<sup>(6,9,22)</sup> the authors addressed patient adherence issues by examining the interrelationship between family or extended kinship networks and the barriers each woman perceived to exist for her use of and adherence to health care services. The secondary purpose of this work was to use information obtained in these interviews to develop a useful methodology for further investigations of the potentially crucial role of the family and/or extended kinship networks in encouraging or discouraging African American HIV seropositive women's use of health care services.

The interview information from the four African American women and their families is presented in a case study format, allowing for an indepth analysis of their use of HIV-related health services from diagnosis through prenatal care and of the actions taken to prevent HIV infection. Observational, open ended, and structured interviews formed the bases for these case studies. The use of case studies was particularly important because the usual forms of reporting group data would not provide a picture of the kinship network of each woman and its relationship to HIV adjustment, health promotion, and health care. Therefore, project staff used genograms (clinical methods for outlining the organization of the family) and sociograms (maps of the connections that families have to formal and informal systems) to probe family relationships<sup>(5,13,20)</sup>.

## Case 1

Jessica (all names have been changed) is a tall, attractive 19-year-old in her seventh month of pregnancy, with no history of substance abuse or conduct disorders. She had been diagnosed with HIV 1-1/2 years earlier when she had visited the public health department "to see a doctor to have a bump removed." While waiting there, she was approached about being tested for HIV and agreed without concern that she would test positive. Although she had several sex partners, she did not consider herself promiscuous or "at risk." She complimented the public health worker who disclosed the HIV diagnosis to her. Jessica said she was told in a way that did not frighten or discourage her and that the "lady explained how she could be healthy a long time if she took care of herself."

When she first learned of her diagnosis, Jessica told two girlfriends, one of whom encouraged her to tell her mother. She chose first to tell the youngest of her aunts, who helped her tell another aunt, who then helped her tell her mother and grandmother. Jessica was most concerned about informing her mother, who she felt would be most hurt by the news. Jessica said that her family took the news fairly well. Her main sense of loss at that time was her belief that she would be unable to have children. Later, she learned that if she became pregnant, there would be a good chance the baby would not have the virus. Jessica did not say that she deliberately got pregnant, but she admitted that she was happy that she "could leave her mother and grandmother a part of herself" after she was gone.

Jessica stated that she never discussed having HIV with the young man who had fathered her baby. He had called her once to discuss his "going to the health department to get tested for syphilis" and that he was "negative." Jessica inferred from this conversation that he had been tested for HIV and was negative. Perhaps this is a rationalization, or perhaps it reflects the difficulty the African American young people in this study had discussing the subject of HIV. At

any rate, the nonchalant way in which Jessica discussed her relationship with the young man suggested that she was not very concerned about him. She stated, "I hope he doesn't come around any more," and had given him the nickname of "creepdog."<sup>[1]</sup>

Jessica reported that prior to her pregnancy, use of condoms was inconsistent at best. Her attitude and behavior suggested that there was a longstanding lack of concern about using contraception and transmitting the virus. In contrast to her earlier lack of regard or knowledge of how to protect her health, during her pregnancy Jessica became a very adherent patient.<sup>[2]</sup> She was genuinely concerned and hopeful about having a healthy baby, so she followed her doctors' advice and rarely missed clinic appointments. Her pregnancy had progressed without complications, and she expected to have a normal delivery.

Jessica's mother Lydia (age 39), her grandmother Lucy (age 60), and her aunt Lottie (age 41) accompanied her to the interview. The family frequently mentioned another aunt, Rhonda (age 30), and an uncle Bernie (age 38) who were not present. Jessica's family was matriarchal in structure with considerable emotional enmeshment. No men—alive or deceased—were given much positive attribute by the family except for Jessica's father who resides in Ohio. All the women agreed that he is a "real good man." Nevertheless, Jessica's mother had left him years ago because she "did not like living in Ohio." As previously stated, Jessica called the father of her expected child "creepdog," appeared to have little concern about him, and no desire to be connected with him in any way. At the time of the interview, all of the women in this family were single, separated or divorced. They were all working full-time and taking care of their children. The family openly joked and laughed about "none of the women in our family have men." Thus, Jessica's attitude about the baby's father was not discouraged in any way by her family and indeed the prevailing family structure was single motherhood and self-sufficiency.

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1 As part of the family interview process, the families were asked to give a nickname to individual family members that would describe each family member's role or characteristic nature.

2 When alone and asked at the end of the interview about future relationships she might have and whether she planned to practice safer sex methods, she stated that she did not want another boyfriend. But, when pressed with "if you change your mind one day and decide to have sex with another boyfriend, will you use condoms?", she said yes.

This "self-sufficiency" existed within a larger interdependent family network of women who assisted one another emotionally (confidence sharing), financially (loaning and giving money), and physically (allowing a family member to "move in" and share a home, or borrow things such as cars and appliances), as well as providing baby sitting and transportation. Everyone in the family seemed to have something unique to offer the others. Each person appeared to be respected for their talent or role within this family network.

Grandmother was described as the center or heart of the family—the one to see for any kind of problem, the one who would always be a source of strength because she rarely sought or accepted help from her children. She had survived two husbands and appeared very proud of the fact that her daughters viewed her as "strong and independent—in fact too independent." They described her as the family member who always provided love and guidance in times of emotional need. The grandmother, who worked full-time, was also seen as a source of financial help and assistance.

Aunt Lottie was viewed as the "educated one." She was described as overprotective, taking her children to the doctor for the smallest of problems. Aunt Lottie was considered "wise" on the whole and often was the leader in making family decisions. She was the family member who advised on business, education, and extrafamilial "systems." For example, when Jessica was approached about participating in this study, she first called Lottie and asked her opinion. Then Jessica had Lottie talk with the researcher about the project. Aunt Lottie, who generally has a positive view of education and the University of Miami School of Medicine, decided that the project was worthwhile and encouraged the family to participate with Jessica.

The family commented on the similarity of Lottie to the grandmother and even stated that she was "in training" to take on the grandmother's role. This family perception was fascinating testament to the intention of this family to perpetuate itself as a "system." While death of the grandmother or "heart" of the family was not being consciously considered, they were nevertheless preparing for it. The "family system" would continue.

Jessica's Aunt Rhonda was viewed as needy and still developing. She was described as being separated from her children's father yet in a persistently turbulent relationship

with him. As a result of these problems, she was having financial difficulties, but was in the process of getting her life together. Rhonda had to draw upon the family resources rather heavily and thus her nickname at the time was "sympathy Sue." Jessica's uncle Bernie was unemployed and also actively using family resources—mostly from the grandmother. Bernie had more "real problems" with becoming self-sufficient, and he had needed assistance for a long period of time. His nickname was "sympathy Sam." The family stated that both Rhonda and Bernie sought help from family members by playing for sympathy, with Bernie possessing a longer history of such requests.

The family suggested that Jessica held a special position in the family because she was the first-born grandchild. They inferred that she had been "spoiled" as a child, and reported that the youngest aunt called her "the princess." It is probably safe to assume that the love and attention Jessica received as a child contributed to her becoming a very gentle, loving young woman. The feelings of love between she and her family were strong and reciprocal.

Jessica lives with her mother, Lydia, and her little sister, Diane (age 11). Diane is not aware of Jessica's diagnosis and was not included in the interview. Jessica's mother is a respiratory technician. She enjoys working in the health field and has encouraged Jessica to guard her health, visit the clinic regularly, and take parenting and health education classes. In fact, Jessica's mother registered them both for a class on HIV, strong evidence of good parenting skills and a positive approach to very difficult circumstances. The family described Lydia as the "medical advisor" of the family—the person family members talk with about health or medical matters. During the interview, she seemed proud of this role, and it was evident that she was actively using her "health related knowledge" to help her daughter. Although all of the grandmother's adult children have their own homes, the family described a lifestyle in which the larger family is together frequently and congregates at the grandmother's house at least once a week.

In the process of learning about how the family members interrelate and function as a whole, good health emerged as a strong family value. Most family members maintained long-term relationships with their physicians. The family, especially the grandmother, seemed accepting of the delays in the Jackson Memorial Hospital's public health

clinics because the quality of care they received was viewed positively.

One of the family's predominant coping skills was humor. They laughed and joked a lot during the first part of the interview. At the end, when the interview focused more on the reality of Jessica being HIV seropositive, the mood became serenely sad. The mother and grandmother sat quietly, tears gently rolling down their cheeks as Jessica openly expressed how much she loved them. She hoped that her baby would be a part of herself that she could leave with them. At that point the grandmother quietly excused herself from the room.

Jessica is an exceptional patient for two reasons. First, she has family support for maintaining a good relationship with physicians and a health care system. Secondly, she is fortunate to be from a supportive middle class family. There are no substantial obstacles to her receiving quality health care. The only threat to her health appears to be her own behavior. If she takes responsibility for her behaviors and her health, she will practice safer sex, maintain a consistent relationship with her physician, and with the HIV related health service system. However, she is young and we can only guess how she will cope with future challenges. Jessica delivered a baby girl, without complications, in December of 1991.





## Case 2

**L**inda is an attractive, intelligent, petite 26-year-old woman with no history of substance abuse, delinquency, or criminality. She likes to read and loves being a mother. She is the eldest of four children. Her mother was 16 at the time of her birth and, like her mother, Linda also was 16 at the time of her first child's birth. At the time of the interview, Linda had four children ranging in age from 9 to 4. The family members who attended the interview were Linda, her sister Patty, age 25, her four children, and Patty's 3-year-old daughter.

Linda had not perceived herself as being "at risk" when she agreed to be tested. Since she received her diagnosis only 4 months prior to the interview, she was still in the process of accepting it. In the interview she spoke about how one woman had a positive test but received a negative result after being tested again. She explained that she was trusting God and was going to get retested. Linda's mother was the first person she told about her diagnosis, calling her even before she left the clinic. Linda describes her mother as the person from whom she seeks guidance and understanding. Linda views their relationship as "very close." She would have included her mother in her family interview, but the mother lived more than 30 miles away and had no transportation. While her mother is obviously her main source of emotional support and guidance, the distance between them prevents Linda's mother from being a day-to-day resource.

Linda, 8 months pregnant, lives with her four children in a three-bedroom HUD duplex in an inner-city neighborhood. Linda does not drive or own a car, has no telephone, and relies heavily on her sister, Patty, for communication and transportation. Patty also was pregnant, but she was only in her fifth month and could move around faster and more easily. Although Linda was cordial and cooperative, she clearly was mildly depressed.

During the interview, Patty was observed actively parenting and caring for all the children. Patty is married,

and does not have to work outside the home. She frequently goes to Linda's house and, during these latter weeks of pregnancy, is there almost every day. Patty and Linda are together so often that they function as co-parents to one another's children. Patty is Linda's primary resource; she supports Linda's medical adherence by taking her to the doctor and other places, helping with the children, and encouraging her to follow her doctor's recommendations. But Linda still is only marginally adherent. Even though Linda's case manager makes home visits to remind her of her clinic appointments, Linda misses many of them.

When asked to identify her major problems with attending the prenatal clinic, Linda responded, "transportation and the actual clinic appointment time." She explained that even though she has a 1:00 p.m. appointment, she is seldom seen before 3:30 p.m. She explained further that most of the time she has to take the two smallest children with her and getting the two of them back home is very difficult. The children get tired, irritable, and often fall asleep. They have to wait for the bus and even transfer buses. Often it is dark before they finally get home and by then she is completely worn out.

Linda had not visited a physician for yearly physicals or regular gynecological checkups. The only time she gets medical care is during a pregnancy. When asked what motivated her to get health care during pregnancy, she answered "the baby's health." Thus, it seems that like many poor minority women, Linda does not seek routine or preventive health care. Only concern for an unborn child or an ill child motivates her to overcome the obstacles to receiving health care. Linda became HIV infected because she was not consistently practicing safe sex. Although she was aware of her history of problematic relationships with men, she was insufficiently motivated to insist that her sexual partners use condoms. Linda recognizes that she chooses "the wrong men to get involved with," but her history suggests that she loses her objectivity in the midst of romance.

Linda's extended kinship network is comprised of older people who live in her neighborhood and a couple of young friends who frequently visit her. She has a few elderly male friends who function in "grandfather"-like roles as sources of practical support (for example, making minor household repairs). However, they do not influence Linda's use of

health care. None of the members of her extended kinship network, except her female church pastor, were aware of her HIV diagnosis. The pastor was a spiritual confidante, who encouraged her to follow the doctor's recommendations, but stated clearly that her primary concern was Linda's spiritual condition. The pastor advised Linda to pray when she became disheartened and depressed. When asked what she would do to cope with strong feelings of depression or loneliness, Linda stated that she would "get on my knees and pray." Praying may be the most adaptive method of coping for a single mother with no immediate means of communication (no telephone) or transportation (no automobile).

Linda had a normal delivery of a baby boy in December of 1991. Although Linda had told her physician, her case manager, and other clinicians that she would have a tubal ligation, she changed her mind and did not have the surgery, which suggests that her ability to bear children is still important even within the context of her HIV infection.



## Case 3

Aretha is a 28-year-old mother of three children ranging in age from 8 to 4. Aretha and her children are supported by welfare (Aid For Dependent Children). She lives in a two-bedroom HUD-subsidized duplex. She has a commonlaw husband, Jack, who is 47 years old. Jack works for a local city's sanitation department. They have been together for more than 6 years. By remaining unmarried, Aretha is able to continue receiving her welfare benefits. Aretha's welfare plus Jack's paycheck provide them with an adequate income for a family of five. They have an old van for transportation and other basic things but their home had no apparent luxuries. Their children were clean and fairly well dressed. One could only conclude that they had no phone out of choice rather than because they could not afford one. Jack is the father of Aretha's last two children and of the child she now carries.

Aretha was a very non-adherent patient. At the time of the interview she was in her eighth month of pregnancy and supposed to attend the special immunology clinic every other week. However, she had not been seen for a month. She was overweight and a gestational diabetic. Aretha's failure to follow a recommended treatment regimen and to keep clinic appointments made her pregnancy difficult to manage. Because she did not have a telephone, her case manager had to make home visits to remind her of clinic appointments and to reinforce medical adherence. When she attended the clinic, she refused to provide a urine specimen, saying that she had to pick up her children at school, and promising to return. She always failed to return.

Aretha had learned of her HIV diagnosis only a few months earlier, during the current pregnancy. At the time of the interview, she had not directly shared news of her diagnosis with anyone except Jack. She mentioned telling her sister and brother about her diagnosis when they were all very drunk. She does not believe they remember because neither had any reaction at that time or since. Jack had so far refused to be tested. His attitude was, "If I have it, I have it

and there is nothing I can do about it, so I don't need to know." Based on clinical experience, Jack's attitude is not uncommon among the African American "at-risk" population.

Aretha and Jack were fully cooperative and appeared genuinely interested in the interview process. They openly responded to the questions and presented questions of their own about HIV infection and its management. Although Aretha was medically non-compliant, she was surprisingly aware of information related to living with HIV and to preventing infection.

Aretha is the youngest of six children. She described her extended family as being fun-loving and social but not very close. Years ago the family met regularly at the mother's house to socialize and gamble. More recently these activities had dwindled and for several months she had stopped attending the family "get-togethers" because she could "not afford to lose that money." Aretha inferred that some degree of conflict or animosity existed among her siblings, but she did not go into detail nor did she express a desire for things to change. In a discussion about the emotional and/or material support she received from her family, she created a picture of almost total isolation. Aretha said that she mainly received emotional support and love from her mother and her children. Surprisingly, she did not acknowledge feeling loved and supported by Jack, even after he subtly prompted her: "what about me?"

Although Aretha reported that she trusted and loved her mother, she did not feel that she could tell her mother about her diagnosis. Aretha openly admitted to feelings of depression and hopelessness. A few days after the family interview she expressed a desire to enter family therapy, but the family did not keep a scheduled appointment. At Aretha's next clinic appointment after the family interview, her doctors discovered that she was not taking her medication properly. They informed her that her baby was at-risk and they unsuccessfully tried to hospitalize her. She again said that she had to pick up her children and promised to return the next day but did not. Within the next days, her case manager and her social worker made several unsuccessful home visits. When Aretha came to clinic the following week she was very forlorn and talked about her feelings of depression. Later that day when the doctors examined her, they discovered that her baby was dead. The clinical staff hospi-

talized her and she delivered a stillborn child. The staff had suspected that Aretha's past reluctance to provide a urine specimen or to be hospitalized was related to substance abuse. However, the baby tested negative for cocaine.

Substance abuse would explain many aspects of Aretha's medical non-compliance, failure to utilize available health care, and social isolation. The isolation that Aretha described was mostly self-imposed, a conscious choice to have less contact with her family. It is possible that her self-isolation could have been motivated by a need to keep her substance abuse a "family secret." Also, it is possible that her health problems could have been complicated by intoxication. During the family interview, Jack and Aretha specifically asked two questions: 1) whether smoking marijuana would have a negative impact on an HIV seropositive person's immune system, and 2) whether or not two infected people still had to use condoms in sex. Since the HIV diagnosis was still new to this family, it is quite possible that their questions suggested areas of their life in which they had to consider behavior change.

Because Aretha had successfully managed three prior pregnancies as a diabetic, she demonstrated the ability to self-medicate. Thus, it is not possible to draw definite conclusions about why she was medically non-adherent during this pregnancy. Perhaps the HIV diagnosis eliminated her motivation to protect her own and her unborn child's health. Substance abuse was only a suspicion, no concrete evidence was ever found, and she repeatedly demonstrated that she was capable of following through on issues she deemed important (for example, coming to the family interview for compensation, and having a tubal ligation). Yet Aretha's case serves as an excellent example of the patient who is non-adherent, but not because of lack of knowledge, inability to understand, lack of transportation, lack of finances for a telephone, or a severe substance abuse problem.

Aretha chose to have a tubal ligation immediately after the stillbirth. She had made a decision about her reproductive capacity and stayed firm in that decision. She did not return for her 6-week postpartum check up. On a home visit approximately 8 weeks after the stillbirth, the project family therapist found that Aretha's depressed affect had diminished, she reported feeling more positive, and generally seemed quite "relieved."





## Case 4

Eilene is a 17-year-old, reticent and doll-faced teenager. She was in the seventh month of her first pregnancy when her family initially was interviewed. Her core family (comprised of family members currently living together) included: Eilene, the youngest of five siblings, her mother (age 52), a pregnant sister Annette (age 21), and her sister's youngest child, an 18-month-old girl. Eilene has two brothers, one who is in prison (age 25), and the other (age 24) who is semi-estranged due to an independent, gay lifestyle. There is limited interaction between the brothers and the core family. Eilene's oldest sister, Michelle (age 35), has a stable marriage with three children. Michelle's husband discourages contact with her family. Nevertheless, Michelle maintains frequent contact, several times each month, to assist her mother.

At the time of the family interview, the family was about to move from their one-room efficiency apartment in Miami Beach because the owner was evicting all the tenants before he remodeled and raised rents. The core family of women were in complete despair. Eilene's mother was overwhelmed by her many problems: 1) the recent loss of her lover to an AIDS-related death, 2) an institutionalized, retarded, and ill brother, 3) two daughters with unwanted pregnancies, 4) a mother with Alzheimer's disease in a nursing home, 5) a brother whom she had not been able to locate for over a year, 6) a son in prison, 7) financial difficulties (total family income less than \$500 a month plus foodstamps), 8) her own HIV diagnosis, 9) Eilene's HIV diagnosis, 10) imminent eviction, and 11) dependency on public transportation.

In the face of these serious difficulties, it would be surprising if Eilene were effectively using the health care system. On the contrary, however, Eilene rarely missed her clinic appointments during her pregnancy and was adherent to her physician's recommendations. Fred, the father of Eilene's baby, was only 20 years old, but he displayed a great deal of maturity and caring by accompanying her to

many of her clinic visits. He patiently waited with her and spent time each day with her at home. Fred worked only part-time at a minimum wage job and was unable to provide financial assistance, but he was attentive and persistent in maintaining his relationship. Eilene's mother initially was resistant to Fred. She viewed him as the source of a problem (the pregnancy) and of no help. Thus, Fred had to make a concerted effort to overcome the mother's initial desire to break up his relationship with Eilene.

As part of routine clinic procedure, Fred, as the sexual partner of the HIV seropositive woman, was counseled about testing for HIV. Fred refused. His attitude, similar to Jack's discussed earlier, was that if he tested seropositive there would be nothing he could do about it. In cases like these, the clinic staff has no recourse but to accept the individual's decision. In Eilene's case, the staff was somewhat relieved to learn that she and Fred were practicing safer sex.

The kinship resources available to this family were practically non-existent. The oldest daughter, Michelle, provided occasional transportation when the mother wanted to go shopping or to visit one of the institutionalized relatives. Michelle was available to help her mother and sisters, but her husband limited her ability to help by discouraging family contact.

After a complicated, extended labor, Eilene gave birth to a boy on February 7, 1992. Both Eilene and the baby remained in the hospital for 2 weeks. During post-delivery, Eilene was treated with IV antibiotics for more than a week due to an increase in syphilis titers. The baby had no medical complications related to syphilis. During Eilene's hospitalization her mother mobilized herself to locate and move into an affordable new apartment, close to the hospital. This new location greatly decreased their public transportation time to the pharmacy, the clinics, the South Florida AIDS Network case managers, and the social security office.

Eilene and Fred (with guidance from her mother) knew how and where to access emergency medical treatment for the newborn baby. To date, Eilene has attended her Special Immunology Post-partum Clinic appointments with the baby exactly on schedule. She and the baby have not had any further medical complications. Eilene's case demonstrates that motivation to use available health care resources can overcome many practical, material and emotional

obstacles to treatment. Both Eilene and her mother have now qualified for social security disability benefits and their financial condition has improved. Eilene and Fred's relationship is intact and they are enjoying their role as new parents.



## Summary and Analysis

As the previous cases demonstrate, there is a broad range of medical adherence among the HIV positive population of African American women in Miami. Applying family concepts and methodologies to empirical health research is a challenge; however, these methods provided much qualitative data and allowed "for appreciating the richness of multivariate family data" <sup>(11)</sup>. Each woman's behavior with regard to her use of health care represents a unique blend of psychological, cultural, socioeconomic, and environmental factors. While additional study would be required to understand more about the interrelationship of these factors, our preliminary work does help identify some key factors for investigation within the Miami African American population. Among the major factors that emerge as relevant to the use of health care services and medical adherence are: 1) transportation, 2) child care, 3) the pregnancy itself (concern for the unborn child's health), 4) the presence of a concerned/involved family member, and 5) substance abuse.

The presence or lack of transportation is a very important factor. Yet, as observed, dependency on public transportation is more of a barrier for some women than others. In the case of Linda, the evening trip home with two small children was a significant deterrent to her keeping clinic appointments. If child care had been readily available, she might have attended clinic more regularly. However, she admitted that she only sought health care during pregnancies, and that her motivation to seek care came from her concern for the baby's health rather than her own. Linda's sister Patty was available to help with child care, but Linda was not sufficiently motivated to coordinate a child care plan with her.

In Eilene's case however, public transportation did not deter her from traveling a much greater distance to attend clinic. Of course, Eilene did not have children or need babysitting, and she had Fred, a very significant other who actively encouraged her use of health care services. Linda

did not have a "Fred." She lacked steady male companionship, and appeared to lack insight as to why her relationships continued to fail. Linda's elderly male friends were limited in the kind of support they could provide.

One outstanding characteristic of Linda's case was how her fundamentalist, religious background provided the foundation for coping with and adjusting to her diagnosis. She adopted a traditional belief system for a supernatural source, "God's will," of her HIV disease and a belief in a supernatural remedy—healing<sup>(12)</sup>. This is a very old, traditional black belief: that if one has sufficient faith and "claims a healing," that God will heal the person—that is if their faith is strong enough.

In cases like Linda's, traditional belief systems and the modern medical model may come into conflict. If one is claiming to be healed, one does not need to go to the doctor (doctors are for ill people). Thus, in Linda's case, if she "claimed a healing," one sign of the strength of her faith will be not visiting the doctor. In fact, Linda stated that she did not like to go to doctors because they talked about things that she disliked. Perhaps the information presented by the doctors challenged her faith that her HIV "retest" would be negative. On a recent inquiry about Linda, her case manager said that she had not returned for *any* postpartum care for herself or her baby. If Linda really "claimed a healing," it also could partially explain why she changed her mind about having the tubal ligation. Having HIV was her primary motivation for getting the procedure. It is imperative in cases like Linda's that counselors, case managers, and doctors attempt to work with patients *within* their belief system and the African American cultural perspective, rather than to contradict it with a philosophy based on the Western medical model<sup>(17)</sup>.

Eilene's case created a special situation because her mother also was HIV positive. Eilene's circumstances incorporated issues of multigenerational family involvement in HIV disease<sup>(8)</sup>. In a clinical setting, the deteriorating physical condition of both Eilene and her mother necessitated a speedy family intervention. Extrafamilial supports and linkages had to be developed for Eilene and Fred to withstand the trials ahead of them.

The positive influence of a caring/concerned family member or significant other also was observed in the case of Jessica<sup>(24)</sup>. One of her family's values was health care. The

family actively encouraged her to keep her clinic appointments, take health-education classes, and maintain proper diet and rest schedules. In this case, we observed that a middle-class African American family not only values basic health care, but also *preventive health care*.

Research has shown that a supportive relationship with the baby's father is an important factor influencing the timing (earlier) of entry into prenatal care <sup>(24)</sup> as in the case of Eilene. However, in cases like Jessica's, where she did not inform her sexual partner about her diagnosis and their relationship ended, it appears that strong family support can be sufficient to influence the use of prenatal care. Jessica had received prenatal care since her first trimester. She did not want support or involvement of the baby's father. Jessica presented as a gentle and loving person who was looking forward to motherhood. This image of Jessica is in stark contrast to someone who would knowingly endanger the life of another by putting them at risk for HIV infection.

In contrast to Jessica, Eilene has the loving support of her baby's father. Yet, according to Eilene's report, she and Fred do not have many reality-based discussions about her HIV status. Eilene's T-cell count was very low, which will continue to cause health risks for both Eilene and Fred if they have unprotected sex; however, they insist that they use condoms. Eilene and Fred remain resistant to discussing the situation and Fred has still not been tested. These cases demonstrate the difficulty that both adolescents and adults have in generating open, reality-based discussions about HIV infection.

A large research survey (N=170) conducted by Thompson and Peebles-Wilkins <sup>(21)</sup> studied the impact of formal, informal, and societal networks on the psychological well-being of black adolescent mothers. They found that although professional support systems are very important, "the single most important informal support providing positive mental health outcomes for the black adolescent mother...was a male partner." Also, their survey suggested that family social support produced more positive outcomes, while peer support sometimes produced negative outcomes. Both of the teenage girls in our study had strong, emotional support from their families and strong relationships with their case managers and physicians. These relationships appeared to maximize their psychological well-being just as suggested in the Thompson and Peeble-Wilkins study.

Aretha's case is an example of how adjustment to HIV diagnosis is further complicated by pregnancy. Her case highlights the importance of having a psychosocial component in prenatal clinics that goes beyond post-test counseling. Receiving an HIV diagnosis during pregnancy is often traumatic <sup>(14)</sup>, and cases such as Aretha's emphasize the need for professional mental health care. Consideration must be given to how the diagnosis might affect both the individual's psychological and medical condition. This is particularly true in high risk pregnancies. Aretha showed evidence of clinical depression. The psychological and behavioral denial she exhibited after learning her diagnosis is a common response <sup>(18)</sup>. It appears that the depression, perhaps coupled with substance abuse, impaired her ability to follow instructions for treating her diabetic condition.

In Los Angeles, Zambrana and associates <sup>(24)</sup> investigated factors that influence prenatal care in a triethnic, low-income population of African Americans, Mexican Americans, and newly arrived Mexican immigrants (Total N=107). Although the sample of African Americans was relatively small (N=20), some important findings were reported. Almost twice as many African American women said they used liquor and marijuana. Only 10 percent of the African Americans reported being advised of medical problems, yet a review of medical charts indicated that 50 percent of them had high-risk pregnancies. Zambrana and associates concluded that this discrepancy indicated a communication failure between caregivers and their clients. The lack of client understanding and medical adherence found in our pilot study with prenatal African American women supports Zambrana and Associates' <sup>(24)</sup> conclusion that communication between "providers and black-American patients needs to be improved."

Client adherence is the result of an interactive process between the health care system providers and the client <sup>(2)</sup>. It is best viewed as a process of "continuous negotiation" <sup>(4)</sup>. Health education research "in drug abuse, hypertension, and cancer suggests that campaigns based on fear backfire...To make and sustain behavior changes—such as practicing safer sex or giving up needle sharing—individuals need to believe that they can take positive action to prevent illness" <sup>(23)</sup>. A sense of personal empowerment rather than fear must be created.



Our study indicates the necessity of taking thorough case histories, which should include the kinship networks and support structures as well as a discussion of the client's real and perceived barriers to care. It suggests that family-systems analysis can identify those individuals who have families/kin/support networks that can assist them in effectively using health services. Also, this study demonstrates the importance of the client's cultural differences and belief systems. The removal of financial barriers to receiving health care does not automatically increase use of care. Time for patient-staff interaction and support services is essential even as resources for HIV-related services become drained by increasing numbers of individuals who are seropositive.



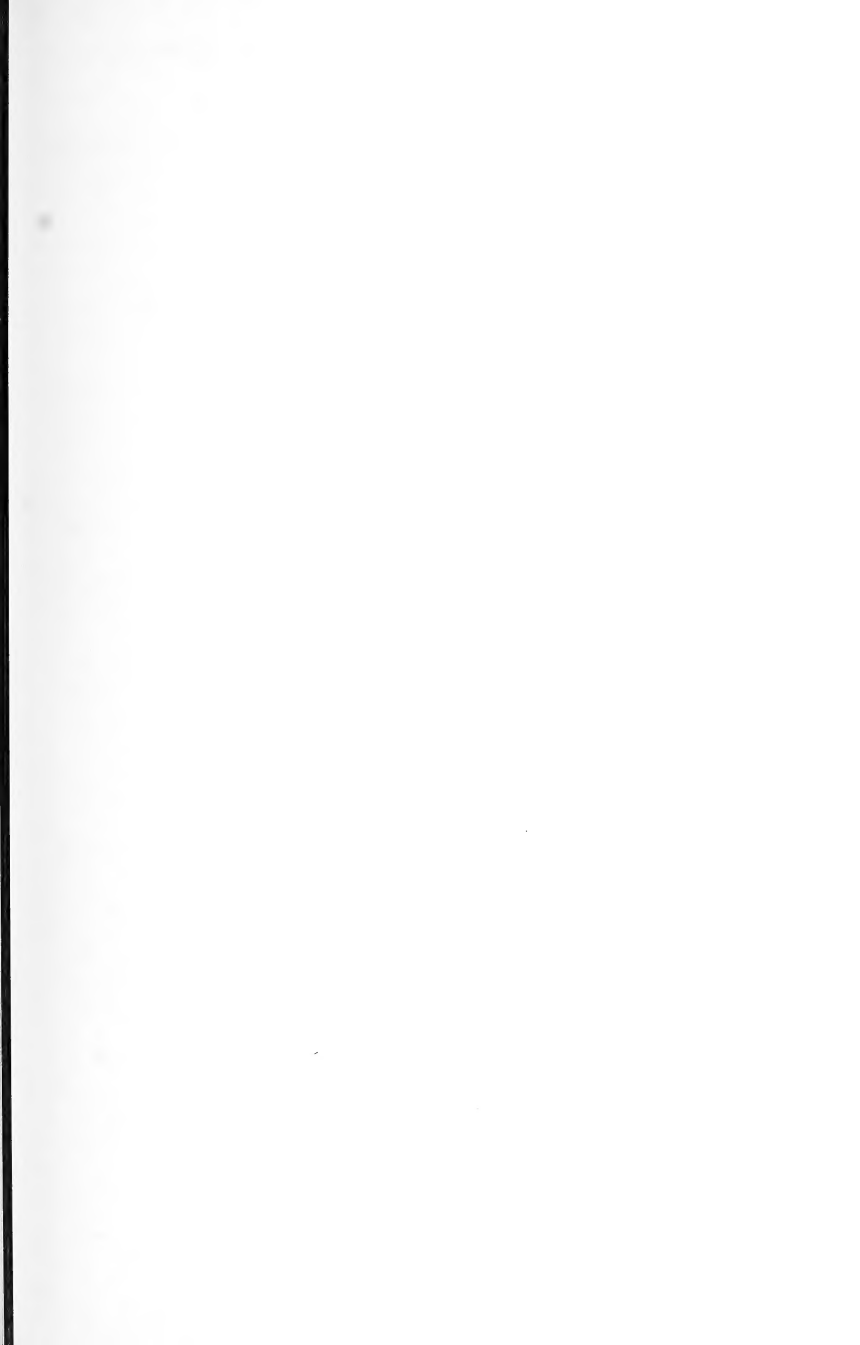
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U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES  
Public Health Service  
Health Resources and Services Administration  
DHHS Publication No. HRSA RD-SP-93-5